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A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units

Received: 10 January 2010
Accepted: 15 September 2010
Published online: 10 November 2010
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Electronic supplementary material

The online version of this article (doi:[10.1007/s00134-010-2074-3](https://doi.org/10.1007/s00134-010-2074-3)) contains supplementary material, which is available to authorized users.

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Abstract *Purpose:* To explore parents' experiences during the admission of their children to a pediatric intensive care unit (PICU). *Method:* Qualitative method using in-depth interviews. Thematic analysis was applied to capture parents' experiences. Thirty-nine mothers and 25 fathers of 41 children admitted to seven of the eight PICUs in university medical centers in The Netherlands were interviewed. *Results:* Parents were interviewed within 1 month after their child's discharge from a PICU. Thematic analysis identified

1,514 quotations that were coded into 63 subthemes. The subthemes were categorized into six major themes: attitude of the professionals; coordination of care; emotional intensity; information management; environmental factors; parent participation. Most themes had an overarching relationship representing the array of experiences encountered by parents when their child was staying in a PICU. The theme of emotional intensity was in particular associated with all the other themes. *Conclusions:* The findings provided a range of themes and subthemes describing the complexity of the parental experiences of a PICU admission. The subthemes present a systematic and thematic basis for the development of a quantitative instrument to measure parental experiences and satisfaction with care. The findings of this study have important clinical implications related to the deeper understanding of parental experiences and improving family-centered care.

Keywords Critical care · Pediatric · Experiences · Needs · Stress · Family-centered care · Qualitative research

Introduction

"I know a PICU is usually quite sterile but human feelings are not sterile and they really do count" [mother].

Admission in a pediatric intensive care unit (PICU) is often a transitional phase in the child's recovery from a critical illness. Most parents experience a PICU admission with a certain emotional impact [1, 2]. In addressing parental stress, many studies have documented the psychological impact of a PICU admission [3]. Other researchers concentrated on parental needs and documented that hope, honesty, accessibility, and information are parents' top priorities [4–6]. Lastly, the overarching themes identified by qualitative studies on parental experiences seem to be related to the role of parents, the parents-professional relationship, and emotional burden [1, 7]. The common outcome of all studies documents a firm impact on the parents.

Only a few validated instruments are available to quantify parental stress or needs in PICU, such as the Parental Stressor Scale: PICU [8] and the Critical Care Family Needs Inventory (CCFNI) [9]. These instruments are limited in that they measure the concepts of stress and needs only. The Parental Stressor Scale: PICU includes items related to care aspects such as environmental factors, communication with staff, and the appearance of the child. Nevertheless, the response categories only relate to the level of stress. A similar limitation applies to the CCFNI, a set of family needs items measuring how important parents rate the needs. In contrast, parental experiences have mainly been assessed via qualitative methods. These studies usually identify four to six themes describing the parents' experiences and often provide valuable information to develop quantitative questionnaires measuring parental experiences or satisfaction with care. Although experience and satisfaction are distinct concepts, to a certain extent they are related to each other [10]. Parents' experiences of a PICU admission are often related to their roles, stress factors, and needs [7, 11]. Satisfaction, on the other hand, has been conceptualized to measure the degree of congruence between parents' expectations and their actual experiences of the perceived care. The key concepts, in this respect, are affective support, health information, decisional control, and professional/technical competencies [12]. Certainly, clinicians must be aware of the parents' expectations, experiences, and satisfaction [13, 14]. Not until then can they optimize family-directed care, meet the needs, and increase satisfaction with care.

A qualitative study was planned to better understand today's parental experiences of a PICU admission [15]. The aim of this study was to explore and to identify accounts of the parents' experiences of a PICU admission of their child.

Methods

In-depth interviews were conducted to facilitate the description of retrospective parental experiences, thereby expanding the general understanding of the parents' experiences of their child's PICU admission [15, 16]. The interviews were conducted between October 2006 and April 2007. The study was approved by the medical ethical review board of the Erasmus Medical Center in Rotterdam and subsequently by the participating centers.

Settings

Of the eight PICUs in The Netherlands, seven participated in the study. In 2007, bed numbers ranged from 8 to 24. Total admissions were 4,840. Patients had a median age of 2.4 years (P_{25-75} 0.4–8.8), stayed a median of 3 days (P_{25-75} 2–6), and needed ventilation for a median of 2 days (P_{25-75} 1–6) [17].

Participants

Parents of six children per participating PICU were recruited, providing a purposive sample per center and nationally [18, 19]. Eligible parents were those whose child had been admitted to the PICU for at least 24 h and who were able to communicate in Dutch. Excluded were parents whose child died during or after the PICU admission to avoid an unnecessary emotional burden and possible differences in parental experiences.

Parents were recruited by the local research coordinators. To avoid selection bias, the recruitment took place on the first day of a predetermined week within the data collection period. Parents were given a written invitation including information about the study, privacy regulations, and contact details of two independent study experts. After parents had provided informed consent, the researcher (JML) arranged for the interview to take place. Parents themselves could choose the time and place of the interview, either at home or in a quiet room in the hospital.

The final planned interview was cancelled because the parents withdrew consent. No new participants were recruited as the last two interviews had revealed data saturation, i.e., similar experiences were addressed with only minor nuances. Thus, 41 interviews were conducted.

Data collection and analysis

The data collection and analysis are described in detail in Appendix 1 (Electronic Supplement Material). In brief, the interviews were held within 1 month after PICU

discharge. A protocol was developed to conduct the interviews. Thematic analysis was performed by using a qualitative data analysis software, ATLAS.ti, version 5.5, Berlin [20, 21]. Descriptive statistics served to calculate frequencies, median, mean, and quartile scores of the characteristics of children and parents using SPSS (version 15, Chicago, IL).

Results

Of the 41 interviews, 23 were held with both mother and father, 16 with the mother only, and 2 with the father only. The children's characteristics are listed in Table 1; the parents' demographics are summarized in Table 2. The mean interview duration was 54 min (range 24–108 min).

Thematic analysis identified 1,514 relevant quotations coded into 63 subthemes. These were clustered into six themes: attitude of the professionals; coordination of care; emotional intensity; information management; environmental factors; parent participation (Table 3). The presented quotations are annotated with study number and an 'M' for mother or 'F' for father. Confidentiality was protected by changing names to an alias. An online supplement of the qualitative findings related to the validity of the subthemes and themes is provided (Table 4, Electronic Supplement Material).

Attitude of professionals

Most parents described their PICU experience from their interaction with the nurses and physicians. From the interviews a vivid picture emerged of how these health care professionals attended to the needs of the child,

Table 1 Characteristics of the children ($n = 41$)

Gender, male	24 (58.5%)
Age in months; median (P_{25-75})	16 (4–75)
Unplanned PICU admission	25 (61%)
Planned PICU admission	16 (39%)
Length of stay PICU; median (P_{25-75})	8 (4–13)
Children on mechanical ventilation (n)	39
Ventilation days; median (P_{25-75})	6 (2–9)
PICU diagnosis	
Cardiovascular	2
Infection	1
Neurology	3
Respiratory	17
Shock-sepsis	1
Trauma	3
Post-procedure diagnosis	
Cardio-thoracic surgery	9
Other	5

PICU Pediatric Intensive Care Unit

Table 2 Parents' demographics

Gender	
Mothers	39
Fathers	25
Age	
Mothers; years, mean (min–max)	35 (19–49)
Fathers; years, mean (min–max)	37 (28–49)
Family composition of children ^a	
One child	8 (20%)
Two children	20 (49%)
Three children	10 (24%)
Four children	1 (2%)
Six children	2 (5%)
Education level mothers	
Lower education	1 (2%)
Middle education	21 (54%)
Higher education	14 (36%)
University	3 (8%)
Education level fathers	
Lower education	4 (16%)
Middle education	11 (44%)
Higher education	8 (32%)
University	2 (8%)
Previous experience of pediatric wards admission	33 (81%)
Previous experience of PICU admission	17 (42%)

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^a Two mothers were single parents

Table 3 Themes and selected subthemes

Attitude of professionals
Awareness of parental needs
Trust in safety
Listening to advice of parents
Coordination of care
Transition PICU to pediatric ward
Teamwork
Having a first responsible nurse
Emotional intensity
First hours of admission
Appearance of child
Critical situations
Information management
Timing of receiving information
Test and procedures
Honesty
Environmental factors
Privacy of a single room
Catering
Sound and light
Parent participation
Involvement in treatment decision-making
Participation in child's care
Presence during test and procedures

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parents, and siblings. Parents whose child was in a PICU for the first time were surprised by the possibilities to make the child's stay as comfortable as possible. The professionals' attitude was also related to behaviors such as empathy, commitment, and respect. Situations on

these subthemes as expressed by many parents were often related to non-verbal communication, such as: *"The attention...yes I can see it from their faces, they do not have to give it, you can read it from the face"* [23:F].

Coordination of care

Parents raised issues documenting inconsistency in the care of their child and themselves. The subtheme consistent work by professionals was related to differences in the nurses' approach and the disparity of care delivery. A PICU is generally a transitional unit. Many parents often experienced differences in the care between a PICU and a pediatric ward, such as: *"That was a weakness of the PICU, they did not..., well, the pediatric ward has no knowledge of trachea canula care. We can do it, but we are not 24 h on the ward, so then there were daily phone calls between the PICU and the ward, and two ward nurses came to the PICU to learn about canula care"* [35:M].

Emotional intensity

In almost all interviews ($n = 39$) parents expressed experiences that reflected a certain level of emotional intensity. Parents' first impressions of the admission tended to be similar as *"you live in a mist"* [11:M]. The stories then often continued with examples representing bewilderment. The uncertainty emerging from these examples was coded as the subtheme 'being in the dark.' The events often raised parental stress levels through a sense of unreality and feeling powerless, for example: *"That we were scared of how we would find him... there is this fear that stayed with you all the time"* [20:M]. In the course of the PICU admission, several other subthemes emerged, reflecting a level of emotional intensity, such as the child's critical illness, its appearance, and seeing other children.

Information management

Most parents provided ideas about improving information provision, particularly the 'moment' of providing information; *"plan more moments to tell how the situation is or what will happen, yes give a little more information between times..."* [17:M]. Many parents also addressed honesty in information provision. Fathers were more outspoken about the need to receive honest information from the clinicians, while mothers often related honesty to a feeling of certainty. A father said: *"The communication of how things are going with your child I found a bit less, you have to pull things out of them... you need to be open to people, being honest"* [15:F]. Parents do appreciate honesty even if the picture of the child's condition is not

complete. Telling parents about any uncertainty might have a positive effect on their trust and security, like one mother stated: *"Briefly they (physicians, nurses) told us how they looked at the current situation, and that showed a lot of uncertainty because they did not know about the diagnosis, and they said in all honesty that they did not know, and expressing uncertainty provides a form of confidence"* [34:M]. Furthermore, discharge planning was addressed by many parents. Many said that timely information on discharge and in the post-PICU period would have helped them to cope with the transition.

Environmental factors

Differences were observed between parents whose child had a single room and those whose child was in a shared room. Generally, a single room was preferred for the privacy and quiet environment. Parents felt then more at ease to express their emotions: *"Yes, you just have more peace in that room, it has more privacy"* [28:M]. Parents also recalled several issues related to the subtheme organization of the PICU, such as the availability of a locker or a notice board indicating who was taking care of their child.

Parent participation

All parents talked about involvement and participation in the care of their child. Regarding treatment decisions, most parents expressed their belief that the physician was the one who should make such decisions. However, the participating centers seem to vary in the level of involving parents in decision-making processes. In one PICU a mother said, *"But I often felt like, who is the professional here? I was so involved while thinking, just do it"* [1:M], whereas in another PICU parents had different experiences, *"They just said this and this needs to be done. We were not asked for our opinion"* [7:M, F]. Many parents appreciated that nurses took the initiative to involve them in the care of their child. Parents did not experience difficulties in the 24 h accessibility. Some parents said that they could stay at night or sleep next to their child. In other cases, most parents did not mind leaving the PICU late evening.

Association between themes

Although the six themes characterize separate areas of care, most of the themes seem to have an overarching relationship representing the continuum of a PICU admission (Fig. 1). Several text fragments were coded with two or more subthemes belonging to more than one theme. The findings and description of the association

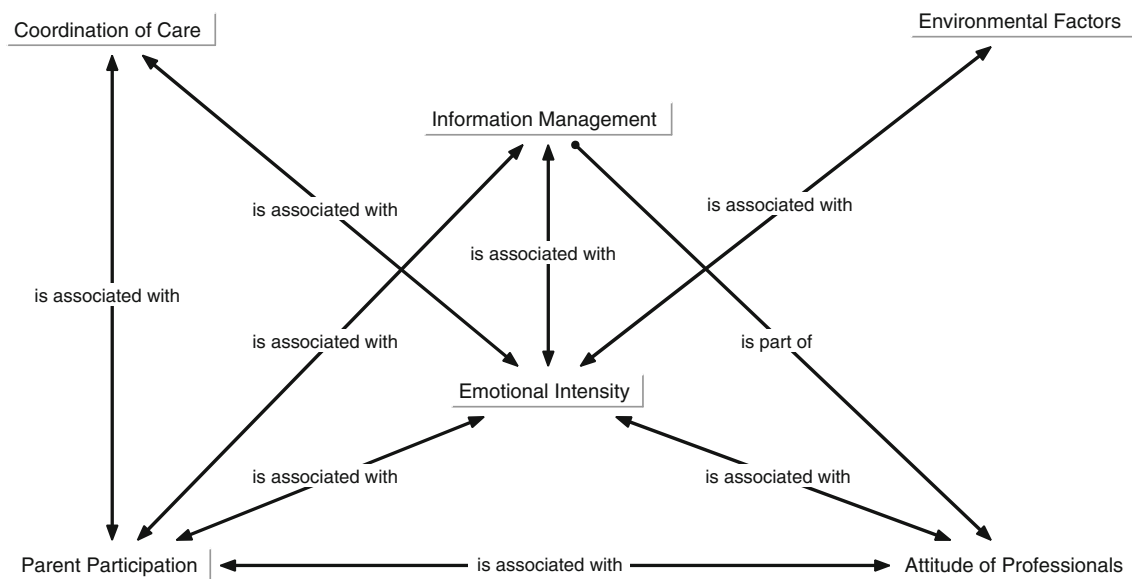


Fig. 1 Associations between themes

between themes are detailed in Appendix 2 (Electronic Supplement Material).

Discussion

The major findings of this study are the 63 subthemes categorized into six major themes reflecting the PICU experiences of the parents. Some themes have been addressed in previous work, particularly ‘emotional intensity’ [22]. Staff communication has also been described as an influencing factor for distress among parents [23, 24]. The findings of the present study provide a more thorough explanation of these concepts, for example by the association among the themes emotional intensity, information management, and professionals’ attitudes. These associations replicate the complexity of PICU care where poor information provision might raise parents’ stress, particularly when parents do not acknowledge empathic staff behavior. A similar association was identified from interviews with parents of children with severe antecedent disabilities in which communication and sympathy within the parent-professional relationship were frequently addressed [25]. Thus, the interaction between parents and professionals seems to be an important factor not only for parents of children with specific health care needs, but for all parents whose child needs intensive care treatment. Besides, from the interviews of the present study, it appears that themes like staff attitude, emotional intensity, and information management play a role from the onset of the admission till discharge. This finding was confirmed in a study exploring psychological outcome among 20 parents

of children admitted to a PICU or to a pediatric ward. Interaction with the medical team was one of the three factors influencing poorer outcomes among PICU parents for the total duration of stay [26].

The use of thematic analysis made it possible to generate an overall description of the PICU services and to analyze the parental stories in a wider concept. Parents often described their experiences of an event and were able to combine facts and emotions into a larger concept. The text fragments brought out evident relationships among several themes. Obviously, a PICU experience cannot be broken down in separate themes. A qualitative study interviewing six parents about their child’s transition from the PICU to the pediatric ward revealed several theme clusters that were sorted into two categories: emotional response and organizational issues [27]. The narrative process of the themes showed that the transition created paradoxical feelings. On the one hand the parents were happy with the child’s health improvement; on the other hand the change in environment led to negative feelings of anxiety or insecurity. The negative feelings were often related to stress due to poor communication and preparation. Using a transfer protocol might help to reduce the negative experiences and increase satisfaction with communication and information [28]. The association of the themes derived from the interviews in our study confirms that any intervention or action is related to many subjects that collectively fit into the overall care delivery and partnership with parents. Therefore, when implementing and evaluating new strategies we must take care to measure not only the content of the process, but also related influential aspects.

Partnership is based on mutual respect and responsibility [29]. Insights into the parents’ experiences allow

clinicians to tailor the care to the individual needs. In addition, various subthemes show similarities with the satisfaction-with-care items emerging from a large sample of parents ($n = 559$) who experienced a PICU admission and from other satisfaction instruments [30–32]. Therefore, the clinical relevance of the present findings can direct health care professionals toward the development of a satisfaction instrument.

A common critique of studies on parental experiences is the lack of views of fathers; they are either underrepresented or not represented at all [7]. While the aim of the present study was to gain a general understanding of the parents, no attempt was made to have an equal number of fathers and mothers. Whether this would influence the findings is debatable since no conflicting text fragments were observed in the interviews with parent couples. In contrast, two studies on stressors among fathers and mothers indeed revealed differences [33, 34]. Fathers ($n = 15$) reported the ‘tube in my child’ as the highest specific source of stress [33], while mothers’ ($n = 31$) most important stressors were ‘injections’ and ‘watching the heart rate on the monitor’ [34]. PICU admission remains stressful and may cause post-traumatic stress in both fathers and mothers [35, 36].

Most children in the study were mechanically ventilated for a median of 6 days; length of stay for the whole group was a median of 8 days. These durations are 4 to 5 days longer than those documented in PICU registries [17, 37, 38]. An explanation could be the period of data collection, which was during the winter months when generally more children are admitted with respiratory syncytial viruses requiring mechanical ventilation. This is also reflected in the relatively high number ($n = 17$, 42%) of respiratory diagnoses. Nevertheless, mechanical ventilation and severity of illness were not of overarching concern within the interviews.

The available evidence on parental experiences originates mainly from the USA and UK [1, 10]. The findings of our study contribute to the body of knowledge of clinicians working in Dutch PICUs. Particularly the identification of several new subthemes might reflect the dynamic changes in socio-cultural contexts. For example, subthemes about safety, medications, and the influence of the media seem to be new areas that might influence parents to have other

expectations. Whether these findings are only relevant for the Dutch PICUs is debatable. Future research is needed to examine the generalizability and transferability of these findings into clinical practice in other socio-cultural settings.

By design, a limitation of this study was the exclusion of non-Dutch speaking parents. Differences in cultural background might result in different parental expectations and experiences. However, experiences of Chinese parents in Hong Kong were comparable to those in the present study [39]. Specifically the role of nurses to support parental participation in care was recognized as valuable in both. Still, it is advisable to further study this issue. Another study limitation is the exclusion of parents whose child died in the PICU. Future research should examine bereaved parents as well because these parents might have different experiences and specific needs, and therefore their support should be directed to individual support and follow-up services [40, 41].

In conclusion, the findings of this interview study are a range of themes and subthemes providing insight into the complexity of the parental experiences of a PICU admission. The subthemes may provide groundwork for the development of items for an instrument measuring parental experiences and satisfaction with care. The clinical implications of the findings might be transferable to other PICUs to gain insight into understanding and collaboration between parents and health care professionals. Then, the momentous transitional PICU period might be less stressful both for the child and the parents.

Acknowledgments The parents are gratefully thanked for participating in this study and providing their valuable experiences. Ko Hagoort and Marjo Frings are thanked for editorial assistance. This study was partially supported by a grant, SNO-T-0501114, from the Nuts OHRA Foundation. The sponsor was not involved in the study design, data collection, analysis, the manuscript, or in the decision to submit the manuscript for publication.

Conflicts of interest The authors have no financial interest or any other conflict of interest to declare.

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